STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

30 EAST 33RD STREET, NEW YORK, NY 10016

SUBMITTED TO THE SENATE COMMITTEE ON FINANCE

HEARING ON " THE COST OF INACTION AND THE URGENT NEED TO REFORM THE U.S. TRANSPLANT SYSTEM"

SUBMITTED BY SHARON PEARCE

SENIOR VICE PRESIDENT, GOVERNMENT RELATIONS

July 20, 2023

The National Kidney Foundation (NKF) respectfully submits our statement for the record on behalf of the 37 million individuals in the United States, 1 in 7 adults, estimated to have chronic kidney disease (CKD).[1] The prevalence of kidney failure is expected to increase dramatically, possibly exceeding one million people who may need access to the transplant waitlist by 2030.[2] There are not enough deceased or living donor organs to meet current or future needs creating a public health emergency that needs immediate attention. Although more than 25,000 people received a kidney transplant in 2022, far too many are still waiting. Many never access the transplant waitlist or learn that a transplant is an option. More than 100,000 individuals are on the transplant waitlist, and nearly 90,000 are waiting for a kidney.

The current transplant system infrastructure has numerous opportunities for improvement to better serve individuals who can benefit from a kidney transplant. NKF has worked to transform the transplant system so that it is more patient-centric, transparent, and equitable. We appreciate the Senate Finance Committee's continued efforts to amplify the critical need for a high-performing transplant system. The lack of appropriate oversight, accountability, and support from regulatory agencies has had life-threatening consequences for the people who rely on the American transplant system for another chance at a healthy life through transplantation. Patients are in dire need of a reformed transplant system that optimizes every single opportunity for organ donation and transplantation.

Approximately 14 people on the national transplant list die each day awaiting their life-saving kidney.[3] Yet, more than 7,000 recovered deceased donor kidneys went untransplanted in 2022, according to data from the Organ Procurement and Transplantation Network (OPTN). Access to transplantation remains disparate for rural populations, communities of color, and people of lower socioeconomic status. Patients highly regard transparency and shared decision-making and desire the same from the stakeholders within the transplant ecosystem. The Senate Finance Committee's 2022 hearing on transplantation uncovered a disturbing array of shortcomings in our national transplant system and identified numerous opportunities for improvement that warrant its reformation and modernization to be best-in-class.

---

[1] Centers for Disease Control and Prevention. *Chronic Kidney Disease in the United States, 2021*. Centers for Disease Control and Prevention; 2021.

[2] McCullough KP, Morgenstern H, Saran R, Herman WH, Robinson BM. Projecting ESRD Incidence and Prevalence in the United States through 2030. J Am Soc Nephrol. 2019 Jan;30(1):127-135. DOI: 10.1681/ASN.2018050531. Epub 2018 Dec 17. PMID: 30559143; PMCID: PMC6317596.

[3] OPTN/SRTR 2021 Annual data report: Preface. (2023). *American Journal of Transplantation*, *23*(2). https://doi.org/10.1016/j.ajt.2023.02.002

Why Patient-Centricity and Transparency Matters

"There does not seem to be any truth in disclosure. I have been on dialysis for three years, and it took two years to meet my transplant team due to the weight I was supposed to be. For two years, I had to struggle on my own with no guidance. They left me out to dry, more like drown, without any safety device."

E. F., NKF Kidney Patient Advocate

Patients are deeply invested in their health and wish to be active participants in decision-making processes along the transplant journey, from initial transplant referral, through the transplant consultation and evaluation phases, through waitlisting, transplantation, and post-transplant recovery. However, inadequate patient education and opacity in transplant program processes make it difficult for patients to make informed decisions. Because transplant hospitals are not transparent about their patient selection criteria, patients do not have the information they need to determine which transplant program will be best able to serve someone with their clinical history or healthcare values.

Even when a patient is able to be listed for transplant, they are often left in the dark about their status on the waitlist. On average, transplant candidates receive 17 organ offers that are declined on their behalf without their knowledge or consent. While those organs are sometimes accepted by and transplanted into other patients with lower allocation priority, in many cases, those declined organs are not utilized at all.[4] Increasing organ utilization is closely linked to reimbursement, transparency, and improved organ acceptance practices. [4] However, it begins with a patient-centered approach to understanding the waitlisted patient's goals and preferences (including preferences that might evolve as time is spent on the waitlist). Transplant programs must always maintain sight of promoting shared decision-making with patients. Patient-centricity must always be a priority, and transplant programs should report on evidence of the inclusion of patients in the decision-making process.

NKF supports patient-centric process measures, including bi-annual reports to patients on organs offered and declined on their behalf and annual conversations between patients and their care team regarding patient preferences and tolerances for accepting or declining certain organs.

The Importance of Equity in Access to Kidney Transplantation

"As a Black patient who has collectively waited more than 14 years on the transplant list, the journey is daunting, and hope is diminished. Time is life when waiting for a life-saving transplant."

M.B., NKF Kidney Patient Advocate

All kidney failure patients must have a fair chance of receiving a life-saving kidney transplant, regardless of their race or ethnicity. Unfortunately, people in underserved communities who want to pursue transplantation as a treatment for kidney failure often face racial, geographic, and socioeconomic barriers. Other hurdles include a lack of patient education and low health literacy which links to the substandard access to transplantation endured by people of lower socioeconomic status, which leaves them reliant upon dialysis instead of receiving the optimal treatment for kidney failure: transplantation.

NKF strongly supports efforts to improve data collection and transparency in the transplantation referral, evaluation, and waitlisting process. The absence of data on the pre-waitlist experience makes it challenging to determine where problems exist. Better data collection would shed light on individual transplant center performance, identify gaps in the system, and would inform policy development to assure that all candidates

---

[4] Husain SA, King KL, Pastan S, et al. Association Between Declined Offers of Deceased Donor Kidney Allograft and Outcomes in Kidney Transplant Candidates. *JAMA Netw Open*. 2019;2(8):e1910312. doi:10.1001/jamanetworkopen.2019.10312

have equitable access to transplantation. Congress and the OPTN could advance this objective by advancing policy that develops a standard definition of a transplant referral and promoting a nationwide system for tracking racial and ethnic disparities in transplant referral, evaluation, and waitlisting.

Saving More Lives by Reforming the U.S. Transplant System

"[Receiving a] Transplant means everything to me. Living on dialysis is very hard. Dialysis is surviving. Transplant is living." A.H., NKF Kidney Patient Advocate

NKF supports reforming and modernizing the U.S. Transplant System to increase and enhance kidney transplantation by upholding patient-centricity, transparency, and equity. We believe that the Health Resources and Services Administration (HRSA) has a responsibility to the American people to create, maintain, and support a high-quality, high-performing transplant system. We look forward to its Organ Procurement and Transplantation Network (OPTN) Modernization Initiative. With increased kidney non-utilization rates, lack of innovation in a world that now has cutting-edge technology, and wide disparity gaps in access to kidney transplantation, we are eager for HRSA to take action to revitalize the transplant system to mitigate the life-threatening consequences of antiquated practices and poor regulatory oversight and accountability.

Conclusion

The National Kidney Foundation applauds the Senate Finance Committee for endeavoring to improve transplantation in the United States. We firmly believe in the achievement of a transplant system that prioritizes patients; it is long overdue. We welcome any questions or comments and stand ready to support Congress in its effort to reform transplantation. Please contact Morgan Reid, Director of Transplant Policy and Strategy (morgan.reid@kidney.org), or Lauren Drew, Director of Congressional Relations (lauren.drew@kidney.org).

Thank you for your consideration.